Hepatitis C (HCV) Network
Needs Assessment

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If you would like more information about the SPRC's HCV project or if you would like to get involved, please contact the Social Planning & Research Council of Hamilton-Wentworth at 522-1148 or sprc@sprc.hamilton.on.ca.

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EXECUTIVE SUMMARY

With support from Health Canada, the Social Planning and Research Council of Hamilton-Wentworth (SPRC) facilitated the development of a local network to improve Hepatitis C (HCV) support and prevention services in the Hamilton area. To this end, the SPRC conducted a needs assessment to determine what such a network might do and how it might function. This report captures what was learned.

In Hamilton, there is a lack of targeted prevention strategies to curtail the spread of HCV. This is exacerbated by a general lack of awareness about the disease. Many people, including health care workers, lack training and information about HCV. As a result, individuals who are at great risk of becoming infected with HCV, or who might already be infected, do not always receive important information about prevention and treatments.

Hamilton also lacks adequate support services for individuals living with HCV (infected) and their caregivers (affected). These individuals often experience HCV-related discrimination, including substandard medical care. (Crofts, Aitkens and Kaldor, 1999) In the face of stigma and marginalization, many individuals are less likely to seek out information and support, which exacerbates the social isolation that is too often associated with HCV.

This report is intended to serve as a resource to address the challenges posed by HCV in Hamilton's communities. The findings of this report are based on information gathered from a range of local stakeholders, including service-providers and people living with HCV. The report contains findings and recommendations that could facilitate the development of a network to improve HCV support and prevention services in Hamilton.

1.0 INTRODUCTION

HCV is a virus that infects the liver and causes hepatitis. It was first identified in 1989. HCV, formerly called non-A, non-B hepatitis, is different than hepatitis A or hepatitis B. The virus is spread primarily through exposure to infected blood. Receiving tainted blood products and sharing unclean needles are common ways in which individuals have become infected with HCV. While it is possible to transmit HCV through unprotected sexual activity, the risk is usually low.

The incidence of Hepatitis C (HCV) is increasing in Canada, as it is across the world. The World Health Organization estimates that between 0.5% and 1% of the Canadian population is infected with HCV. (World Health Organization, 2000) The number of individuals who are infected in Canada is estimated at 240,000. (1st Canadian Conference on Hepatitis C, 2001) Most of these individuals do not know that they are infected. Some may have been infected through seemingly harmless practices such as tattooing and body piercing. Currently, 70% of all new HCV infections in Canada each year are attributed to sharing needles and other drug equipment. (Taylor, 2001)

Like other infectious diseases, HCV disproportionately affects individuals that experience social marginalization. While HCV is a potential health problem for all Canadians, certain groups are most at risk. These include injection drug users, prisoners, Aboriginal Canadians, street-involved youth and women. (Taylor, 2001) Living with HCV is often associated with poverty, discrimination and drug addiction. HCV is also frequently a problem for individuals who are coping with other chronic illnesses such as HIV/AIDS and hemophilia.

The potential impacts of HCV on society are enormous. While there is, as yet, no cure or vaccine against HCV, some promising treatments are in the pipeline. In the meantime, targeted prevention efforts are the best response to curtailing the spread of HCV. For those who are currently living with HCV, improving quality of health care is critical. Improving access to treatment information and training health care workers are two important steps in that direction.

2.0 SUMMARY OF KEY FINDINGS

Through direct consultation with service-providers and people living with HCV, the needs assessment identified a number of key issues regarding HCV services in Hamilton. Using various methods, including a questionnaire, focus groups and interviews, the needs assessment sought specific information about service priorities, particularly for populations that are most at risk for HCV infection. The following service issues represent broad, qualitative findings. For more detailed information, please refer to the Key Findings section (Appendix A) of this report.

The needs assessment uncovered the following general problems with respect to HCV prevention and support services in Hamilton.

1 **There is not enough collaboration in the community.**

Currently, service-providers are not collaborating extensively in the development and delivery of HCV services. Many HCV service-providers are not sure how best to connect with others in the community. Many service-providers have a specific mandate and serve specific populations. Others operate in the larger sphere of the health care system. The diverse range of organizational approaches and priorities means that HCV-related services are not always well integrated. Many service-providers, especially voluntary sector organizations, are struggling to develop the resources to deliver their services, let alone expand them. Service-providers must maximize their resources through collaboration if they are to meet the range and extent of HCV-related need in Hamilton. Although they could bring valuable "lived" expertise, people living with HCV are not extensively involved in the design and delivery of services.

2 **Service providers require training.**

Many service-providers, including health care workers, are struggling to acquire the knowledge and skills to effectively serve the needs of people living with HCV. This is especially the case where marginalized individuals, such as injection drug users, are concerned. Many service-providers require training with respect to clinical practice, targeted outreach, harm reduction, counselling issues and community referrals. Due the relative "newness" of HCV as a health care problem, many service providers still require training in these areas.

3 **Important information is not easily accessible.**

There is a lack of easily accessible information about HCV, which is a problem for both service-users and service-providers. Information is especially needed with respect to prevention and treatment. What does exist is either difficult to find or not appropriate in terms of language, culture or method of delivery. Marginalized groups that most need HCV-related information are often the most difficult to reach and, therefore, largely under-serviced.

4 People living with HCV lack adequate supports.

The burdens of discrimination and social isolation are frequently a part of living with HCV. Many people living with HCV are hesitant to tell their family, friends and co-workers. Many are living alone with their diagnosis. Opportunities are needed to assist people living with HCV to develop connections with one another. Such connections can decrease isolation and improve quality of life. This is especially true for individuals from marginalized groups with few social supports.

5 There is a lack of awareness about HCV.

Target groups, as well as the broader community, need to understand the potential impacts of HCV on individuals and society. Generally speaking, most people do not know about the risks associated with HCV transmission, leading to a situation where individuals, especially from marginalized groups, are becoming infected with HCV. Where there is a lack of awareness about HCV, there is also more likely to be discrimination and social isolation.

3.0 RECOMMENDATIONS

What is needed to develop HCV services in Hamilton?

3.1 Building A Network

A multistakeholder community-based network should be established to enhance Hamilton's capacity to provide a sustainable response to the challenges posed by HCV in its communities. The network should facilitate the development of local services by mobilizing a range of community resources. It should serve as a focal point for service issues associated with HCV, especially those related to marginalization, medical care and peer support.

The network's main objectives should be:

1. to foster collaboration amongst stakeholders, including service-users and service-providers
2. to assist service-providers with skills-building
3. to improve access to HCV-related information
4. to assist people living with HCV with peer connections
5. to raise awareness of HCV

Such a network requires a coordinating body and additional resources to actualize its objectives. In order to move forward with the proposed recommendations, a sponsor agency, such as the Social Planning and Research Council, should facilitate the formation of a multi-stakeholder working group, comprised of both service-users and service-providers. The working group should form the core of the network, expanding it to involve community stakeholders as the project develops. This approach would maximize the sharing of perspectives and expertise. It would also foster community development. Local stakeholders, including people living with HCV, have expressed a strong interest in helping to develop such a network.

The working group should play a key role in prioritizing and implementing the proposed recommendations. A formal structure with terms of reference, the working group should also be instrumental in guiding a workplan for the next phase of the project. Other possible functions for the working group should include promoting the network, recruiting members and evaluating the project's outcomes.

3.2 Fostering Collaboration In The Community

The network should assist stakeholders to network and develop partnerships. This includes community-based organizations, public health departments, hospital clinics and community health centres. It also includes people living with HCV and their caregivers. Multistakeholder partnerships are critical to developing effective services, especially those that involve marginalized communities.

1. The network should play a supportive role at all levels of collaboration, from formal partnerships to community networking to peer mentoring to resource exchange. It should help organizations to identify possible opportunities for collaboration. To facilitate this, the network should compile and provide a "catalogue of community partners". This would contain profile information about member organizations, including their service needs, program objectives and professional expertise. It would also contain examples of current community partnerships. Such an approach would help service-providers to identify potential opportunities for collaboration. It would foster the development of new and existing services, as well as prevent the duplication of services. It would also bring together a range of resources and expertise in the community for the purpose of service development.

2. People living with HCV and their caregivers should be involved, wherever possible, in the design and delivery of services. Where possible, organizations should develop opportunities such as volunteer placements to involve service-users. Service-users should also have regular opportunities to provide input in the planning and evaluation of HCV services. Involving service-users also entails removing barriers, such as discrimination, that sometimes exist within organizations.

3.3 Training Service-Providers

The network should assist local service providers with HCV-related skills building.

1. "Train the trainer" tools should be developed to assist staff at organizations that frequently provide services to people living with HCV, or are at high risk of infection. This includes shelters, health care facilities and addictions services. The focus here should be on training needs related to general knowledge (HCV 101), treatment issues, diagnosis/testing and psychosocial issues related to serving marginalized individuals. The tools could also be adapted and used for service-users of those organizations. This training should be promoted in a targeted fashion to organizations that serve individuals who are most vulnerable to HCV infection.

2. The network should also facilitate the development of training opportunities specifically for health care professionals, including developing a clinical practice "checklist" for family doctors and nurses. This training should also include information about diagnosis, prognosis, treatment and harm reduction. Health care workers could lend their expertise to the design and delivery of this training.

3. The network should facilitate the availability of various opportunities, such as workshops and conferences, to address the following general training needs:
    i. evidence-based health practices regarding HCV, including treatment updates
    ii. prevention education, including targeted outreach and harm reduction
    iii. peer counseling for people living with HCV and caregivers

4. The network should facilitate collaboration amongst service-providers by developing peer mentoring opportunities, whereby service-providers with expertise regarding HCV could share this knowledge and experience with less-experienced service-providers, especially around issues related to harm reduction, targeted outreach and treatment issues.

3.4 Making Important Information Accessible

The network should be a focal point for organizations and individuals that are seeking current, accurate and understandable information on issues related to HCV. The focus of this information should be on prevention and health management for target groups.

1. A centralized referral tool should be developed to assist stakeholders to find HCV-related information. The tool could take various forms, including an information sheet or web page. It would link stakeholders to the network itself, as well as to specific sources of information. It could provide links to pertinent websites, including those of local service organizations. The referral tool could provide a listing of key community services, including such services as assistance with compensation claims, treatments and support. It could recommend pamphlets and other education materials, as well as how to obtain them. Such a listing would help organizations to make referrals. At the same time, it would help people living with HCV to locate services.

2. The network should employ creative strategies to ensure that needed information is accessible to marginalized groups by providing it in a variety of manners, including peer exchange and community outreach.

3.5 Increasing Support For People Living With HCV

The network should facilitate the development of capacity amongst individuals and communities most at risk, infected or affected by HCV, in order to promote community development, empowered self-care, peer education and support. Peer support opportunities should be developed for people living with HCV and their caregivers with a focus on marginalized groups.

1. Opportunities for service-users to connect with one another in various ways should be developed. These opportunities should allow for confidentiality and diversity. Peer support groups, chat rooms, listservs and message boards could facilitate such connections.

2. The network should facilitate the involvement of service-users in all its functions as a way of bringing people living with HCV together, especially from different target groups. In this way, the network could help service-users to identify and pursue shared interests with respect to living with HCV, including access to better health care, access to harm reduction practices and access to adequate supports.

3.6 Raising Awareness About HCV

While the focus of the network should be on the needs of target populations, opportunities should be developed that would allow for more general awareness about Hep C. Without more public awareness, people living with HCV are likely to continue experiencing discrimination and stigma, and those who are at high risk of becoming infected will not be as likely to take precautions.

1. The network should be a forum to encourage links between organizations and initiatives that are primarily focused on HCV with those that are focused on overlapping community concerns such as poverty, racism, HIV/AIDS and drug addictions. Service-providers could seek out opportunities to raise the profile of HCV within their organizations, including de-tox facilities and detention centres, that may have important but less direct links to HCV. Service-providers could look for opportunities to integrate HCV in the work of their organizations, including training for staff and clients.
   - The network should facilitate opportunities to raise the profile of HCV within the general community, including taking part in events such as health fairs.

These recommendations are based on a set of priorities identified by those organizations and individuals who participated in the needs assessment. While the network would strive to involve as many of these recommendations as possible, it may not be possible to do so, depending largely on the availability of community resources.

The recommendations are possible starting points and may require further shaping by the project's working group.

4.0 METHODS

4.1 Questionnaire

The questionnaire was designed to provide baseline information about HCV-related service issues in Hamilton. It was also intended to shed light on priorities related to service provision. Rather than investigating specific issues, the questionnaire sought general feedback as a way of validating anecdotally identified needs in Hamilton, as well as those identified through a review of the literature. The questionnaire was sent to 47 organizations that provide health and social services to populations with a high incidence of HCV infection. Twenty responses were received, representing a response rate of 43%. The questionnaire and its results are presented in appendix B.

4.2 Focus Groups

Focus groups were conducted with both service-providers and people living with HCV in order to understand specific priorities for HCV-related services. Fifteen key health and social service organizations were invited to participate, including local community health centres, the Canadian Liver Foundation, the Hepatitis C Society, the Hamilton AIDS Network and Hemophilia Ontario. Of these, representatives from ten organizations participated. A call for people living with HCV to participate was issued throughout the community, largely targeted at health care facilities. Fourteen individuals volunteered to participate. Of these, only four attended the focus group. Outlines for the focus groups are presented in Appendices C and D.

4.3 Interviews

In order to explore issues identified through the questionnaire and focus groups, interviews were conducted with individuals responsible for the planning and implementation of similar HCV programs in Kingston and Ottawa. The interviews were intended to provide comparative data with which to assess the results of the questionnaire and focus groups. Outlines for these interviews are presented in appendix E.

It should also be noted that individual, informal interviews were conducted with six people living with HCV. These individuals were either not able to participate in the focus groups or were not comfortable enough to do so.

4.4 Research Limitations

While efforts were made to consult people living with HCV, this proved difficult. This was likely related to the social isolation and marginalization that pose unique challenges in reaching people living with HCV. Some individuals living with HCV were more comfortable providing feedback by phone, which allowed a greater degree of privacy. In addition, many individuals living with HCV are not well-connected with community organizations, which made access to this population all the more difficult.

The results of this needs assessment are intended to provide a framework to inform the further development of a local HCV network. The results are not exhaustive. Instead, they represent the beginning of a longer process to develop HCV services in Hamilton.

5.0 KEY FINDINGS

The following problems were identified by the needs assessment. These problems represent the combined findings of the questionnaire, focus groups and interviews. They are reported in two broad categories:

1. Using services
2. Providing services

5.1 Using Services

5.1.1 Stigma and Discrimination

- Many people living with HCV experience stigma and are afraid to disclose their HCV status, even to family and friends. This stigma probably stems from general ignorance about HCV, particularly a lack of awareness about how the virus is transmitted. For some people living with HCV, the stigma is exacerbated by the perception that those who contracted HCV through drug use or other personal practices, such as tattooing or sexual activity, are "to blame", whereas those who became infected through blood products are "innocent victims." For many individuals, the stigma of being infected with HCV is compounded by discrimination, including racism and classism.

5.1.2 Social Isolation

- Difficulty with disclosure leads to social isolation, including estrangement from potential sources of support such as family and friends. People living with HCV often feel that they are alone, knowing few, if any, other individuals who are living with HCV. Many lack opportunities to share concerns with others who are living with HCV. This exacerbates their sense of isolation. It also exacerbates stress regarding the potential impacts of HCV on their lives. Anxiety and uncertainty about the future are common realities for people living with HCV and their caregivers. They may feel angry and frustrated over limitations to career, lifestyle, child care and financial security. Without a means to exchange personal experience with peers, many people living with HCV must grapple alone with new and complicated issues, including treatment options, disclosure, managing symptoms and accessing community services.

5.1.3. Inadequate Treatment Information

- People living with HCV in Hamilton lack access to information about a range of medical concerns, especially information about disease progression, treatments and prevention. Individuals often manage their health without adequate information about prescribed treatments, including side effects and drug interactions.

Treatment information that is available tends to exist in isolated organizational pockets or on the Internet. Such sources are largely inaccessible to many people living with HCV due to such factors as low literacy, poverty and incarceration. People living with HCV are often overwhelmed by the scope, complexity and constantly changing demands of managing their health, including keeping abreast of treatment options, exploring complementary therapies and juggling multiple prescriptions. Individuals, especially those with multiple health problems, need information about the potential effects of combining treatments for HCV with other treatments, everything from Tylenol to HIV anti-retrovirals to St. John's wort.

5.1.4. Inadequate Health Care

- People living with HCV often experience frustration in dealing with health care providers, including family doctors, nurses, dentists and emergency room personnel. They feel that many of these professionals do not have the knowledge to deal effectively with HCV, especially in combination with other health problems such as HIV/AIDS and addictions. In Hamilton, hepatologists (liver specialists) are in high demand. As a result, many of these doctors do not have the time to provide extensive care and information to their patients. A symptomatic individual might receive specialized care once every six months, and then only during a short appointment. This, coupled with the fact that primary care is inadequate, makes access to good health care difficult for most people living with HCV.

5.1.5 Multiple Life Challenges

- Accessing services is especially challenging for people who are marginalized and coping with numerous health and social challenges. Those who face poverty, addictions, homelessness, discrimination and incarceration are less likely to seek out and receive information and support. Coping successfully with HCV, therefore, is often dependent on one's socioeconomic status. Many people living with HCV are also dealing with other chronic conditions such as HIV/AIDS, addictions, hemophilia and mental illness. This means that HCV must compete with other, sometimes more pressing, health issues.

5.2 Providing Services

5.2.1 Service Shortage

- HCV is a priority for a range of organizations in Hamilton, especially those who provide health and social services to groups that are disproportionately affected by HCV. While service providers are generally familiar with available HCV-related services in Hamilton, they agree that these services fall short of meeting the medical and psychosocial support needs of people living with HCV.

5.2.2 Inadequate Information

- Service-providers need information about various aspects of HCV, including transmission/prevention, testing, disease progression, treatments and psychosocial issues. They also need information about the range of community services and resources that are available in Hamilton. Many people living with HCV rely primarily on service-providers, especially health care workers, for up-to-date information about HCV, including referrals to community resources. Many health care providers are not equipped to provide this information.

5.2.3 Lack of Professional Training

- Service providers would benefit from a range of training opportunities. Health care providers, for example, often lack the training and resources to provide appropriate care to people living with HCV. Many health care workers, including family physicians, are not well-versed with HCV, including diagnosis and treatment. Addictions, especially to injection drugs, are frequently associated with HCV infection. Training service-providers to understand and integrate harm reduction strategies in service delivery is critical. Training areas might include needle exchange, methadone treatment and addictions counselling, which are critical to effective HCV treatment, support and prevention. Service-providers must integrate HCV treatment issues with care for other conditions, especially drug addictions.

5.2.4 Lack of Targeted Services

- Due to stigma and marginalization, individuals living with HCV are often difficult to reach and frequently do not seek out formal services. The fact that people living with HCV represent a diverse range of backgrounds and communities makes it all the more difficult. In addition, many individuals who contracted HCV through blood products are often not connected to target communities and, therefore, also difficult to reach. Innovative outreach strategies are required to ensure that all people living with HCV receive accessible and appropriate services. These strategies must include concern for confidentiality and diversity. For example, some people living with HCV might join a support group, while others would prefer to connect more anonymously through electronic communication (e.g. chat lines, email, message boards).

5.2.5 Inadequate Collaboration

- More dialogue and collaboration are needed amongst service providers, as well as between service-providers and service-users. It is important to remove "us/them" barriers between service-providers and service-users. Involving people living with HCV in the development of services is critical to devising community-based, effective approaches to HCV prevention and support. Using culturally specific, creative strategies will increase trust and remove barriers to service use, including perceived discrimination, language differences and class distinctions. Collaborating

"outside of the box" is critical to providing services, especially to marginalized groups. Service-providers from different sectors and disciplines must work together. This might include a detention centre, a pharmaceutical company, government, health care facilities or a grassroots organization. The needs and issues of people living with HCV are diverse. A multistakeholder, multidisciplinary approach is essential.

6.0 REFERENCES

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Appendix A

Hepatitis C (HCV) Network - Needs Assessment - 2001
Questionnaire - Results
(n = 20)

Mean values are indicated for each response according to the following scale:
Strongly agree (1) Agree (2) Disagree (3) Strongly disagree (4) Don't know (5)

1.	HCV is currently a priority for my organization?	2.4
2.	In my organization, we provide services that:	
a.	address the medical needs of people living with HCV	2.6
b.	address the support needs of people living with HCV	2.5
c.	address HCV awareness/prevention in the community	2.5
3.	At the current time, my organization regularly provides HCV services to:	
a.	injection drug users	2.3
b.	street-involved individuals, including youth	2.2
c.	prisoners	2.8
d.	gay and bisexual men	2.5
e.	aboriginal people	2.3
f.	people who have received blood transfusions	2.9
4.	In the Hamilton area, I am familiar with:	
a.	medical/clinical services that specifically address HCV	2.2
b.	support services that specifically address HCV	2.5
c.	education/prevention services related to HCV	2.4
5.	In the Hamilton area, there are adequate services to meet:	
a.	medical needs of people living with HCV	4.2
b.	support needs of individuals infected/affected by HCV	4.4
c.	needs related to preventing HCV infection	4.4
6.	I would benefit from learning more about:	
a.	what HCV is	2.4
b.	transmission/prevention of HCV	2.2
c.	testing and diagnosis for HCV	2.1
d.	prognosis/clinical profile for HCV	2.1
e.	treatment options for HCV	2.1
f.	HCV-related research	2.5
7.	In the Hamilton area, I need more information about:	
a.	medical services for people living with HCV	2.0
b.	support services for people infected/affected by HCV	1.8
c.	targeted prevention for groups at greatest risk	1.9
d.	ways to challenge discrimination associated with HCV	2.0
8.	To improve HCV-related services in my organization, I would take advantage of:	
a.	training opportunities related to prevention or support	1.9
b.	internet-based information about HCV (e.g. listserv)	2.0
c.	educational resources about HCV (e.g. pamphlets)	1.7
d.	partnership opportunities with other organizations	2.2

Appendix B

Hepatitis C Project - Needs Assessment

Focus Group: Service-Providers

Key Questions

1. What do you think are the main issues for people living with HCV?

2. Which populations are in greatest need of HCV services in Hamilton?

3. What are important service issues with respect to HCV in Hamilton?

4. How could a network help organizations to develop and deliver HCV services?

Appendix C

Hepatitis C Project - Needs Assessment

Focus Group: Service-Users

Key Questions

1. What are important issues for people living with Hepatitis C?

2. What is working well with respect to services in Hamilton? What is not?

3. What might help to improve services for people living with Hepatitis C in Hamilton?

4. How might people living with Hepatitis C participate in a network?

Appendix D

Hepatitis C (HCV) Project - Needs Assessment

Outline: Key Informant Interview

Key informant: manager/coordinator of community-based HCV project in Ontario

Length of interview: 45 - 60 minutes

Questions

1. What are the main objectives of your HCV project?
2. What do you consider to be important issues for people living with HCV?
3. What do see as service priorities with respect to HCV?
4. In your area, what is working well with respect to HCV services? What is not?
5. What are some of the challenges that organizations face in developing or providing HCV services?
6. In your experience, which populations/groups are in greatest need of HCV services? (What are the target populations for your project?)
7. Do target populations experience barriers with respect to service access? If so, what are they?
8. In your opinion, how could a community-based network bring service providers and service users (i.e. people living with HCV) together for the purpose of improving HCV services?